

# INSTRUCTIONS FOR THE SEMI-ANNUAL FOLLOW-UP GENERAL INTERVIEW QUESTIONS (01/22/2025) (GNK, VERSION 1, 01/13/2025)

#### I. General Instructions

The semi-annual follow-up general interview questions (GNK) are completed during the semi-annual follow up interview following the semi-annual follow-up core questions (SAF). The GNK interview is **not** administered to proxy respondents or contacts who answer the SAF questions about the ARIC study participant, nor is the GNK interview administered to ARIC participants who refuse the SAF.

## II. Detailed Instructions for Each Item

- 0a. Enter the date of the interview. This date should fall between the scheduling windows on the Semi-Annual (Participant) Tracing Report.
- 0b. Enter the staff ID for the telephone follow-up interviewer ID.

# A. Physical Activity

1. In general, you are trying to assess the participant's current physical activity levels with a single question. This single question was selected from the ARIC/Baecke Physical Activity Questionnaire, collected at Visits 1, 3, 5, 6, and 7 to quantify participant physical activity levels.

# <u>Read the question as listed</u>: "During leisure time, how often would you say you play sports or exercise?"

The focus of this question is to determine the participant's current levels of physical activity. The five possible response options range from "never" to "very often".

This question pertains to usual leisure time physical activity. Walking and other light physical activities would be included in sports or exercise.

#### **B. Functional Status**

This question applies to the participant's current functional status within the last 4 weeks rather than on the day of the interview. We do not want to document changes in functional ability that might be due to temporary conditions such as a headache, a cold or the flu, or a sprained ankle, etc. The intent of these questions is to record the individual's overall ABILITY to perform the listed activities (i.e., heavy work around the house, walk upstairs without assistance, walk half a mile, or work outside the home).

# Read the question as listed: "Are you able to do your usual activities, such as work around the house or recreation?"

2. The focus of this question is to determine whether the ability to pursue one's normal activities around the house has been compromised by poor health. If a participant indicates that s/he is

able to carry on with the usual activities around the house, but is not able to do his/her usual recreational activities -- such as walking, or performing any form of recreational exercise which they have been able to do until recently, record the question as "No".

Read the following text aloud if there are concerns about multiple questions related to the participant's ability to walk: "As part of this questionnaire, we will ask several questions about your ability to walk. Those questions may sound very similar, but they are slightly different and each one is part of a different smaller set of questions. We thank you very much for your patience as we ask you each of these questions."

<u>Read the question as listed</u>: "Are you able to walk half a mile without help? That's about 8 ordinary blocks."

3. Again, the emphasis is on the ability to do the activity, in this case, to walk half a mile. The concept of help in this item refers to persons helping. Therefore, the use of equipment would not be considered assistance and you would record the question as "Yes" for a participant who reported walking half a mile with the use of a cane or a walker if they are able to use it independently. It is assumed that anyone requiring a second individual to assist ambulating is not able to walk half a mile.

# Read the question as listed: "Are you able to walk up and down stairs without help?"

4. The focus of the question is on the participant's ability to walk up and down stairs without the assistance of another person. If the participant responds that they live in a house (such as a ranch house) where they do not have stairs, say that you want to know if he/she is able to walk up and down stairs if necessary. If the participant responds that they use a seated stair-lift to get up stairs, but can access and use the lift of their own accord, record the question as "No". If the respondent is uncertain, record the question as "No".

# Read the question as listed: "Are you able to do heavy work around the house without help?"

- 5. For this question, it is recommended that you provide the participant with some examples of heavy work around the house. Examples of heavy work around the house may include:
  - Shoveling show
  - Washing windows
  - Cutting the grass with a hand or power mower (but not a riding lawn mower)
  - Painting walls or wallpapering
  - Cleaning the kitchen oven
  - Cleaning the bathroom

If the participant states that they do not perform heavy work around the house, the interviewer should ask again "Are you able to do <u>any</u> heavy work?" Additional examples of heavy work can include: carrying heavy loads (such as grocery bags from the store to the car) or (manually) washing a car. These additional tasks can be performed even by those

participants who live in retirement communities or assisted living facilities and may not be exposed to heavy work.

## C. Falls

# <u>Script</u>: "Next, I will ask you about falls you may have experienced during the past 12 months."

A fall is a sudden, unintentional change in position that causes landing at a lower level, on an object, the floor, or the ground. Do not include reported falls that occurred due to sudden paralysis, a seizure, a stroke, syncope or fainting, or being pushed.

- 6. Ask the participant if they have fallen in the past 12 months. If they answer "Yes" proceed to question 7. If they answer "No" or "Do not remember" proceed to the question 8.
- 7. Ask the participant "In the past 12 months, how many times did they fall?" The answers are 1, 2, 3, 4, 5, 6 or more, or "Do not remember".

# D. Caregiving

- 8. Read the question as listed: "Are you currently receiving care on an ongoing basis to help with chronic illness or disability? This includes any kind of help, such as companionship, help with dressing, bathing, transportation, food preparation."
- 9. This question provides information on the extent to which the person receiving care is in constant contact with the caregiver. It is possible that the caregiver is living in the same dwelling as the care recipient, although the care recipient may spend the day in a full-day care facility. This should still be considered as living with the caregiver. The answer to this question should be "Yes" if the person receiving care is living in a long-term care facility where s/he is receiving care on a regular basis. It should also be "Yes" if the person is living in an assisted living facility. For individuals, who state that they live in a retirement community, the answer will be "Yes" to this question if they also receive help with daily activities, having transitioned to assisted living or to skilled nursing to receive more medical care while remaining in the same community.

#### E. Vaccination

10. If necessary, remind the participant of the current date and ask if they have received a flu shot since that date last year. For example, if the date of the interview is March 28, 2024, ask if they have received a flu shot since March 28, 2023.

## F. Digital Access

<u>Script</u>: "Next, I will ask you about your access to different types of computers and the internet."

For questions 11a-11c, record whether the participant owns any of the following types of computers. Participants who state they do not own a device but use someone else's computer

(e.g., that of a spouse, child, or publicly available device) should be marked as "no" for not owning said computer.

- 11a. A smartphone is a mobile phone that performs many of the advanced functions of a computer. It typically has a touchscreen and internet access and is capable of downloading applications or "apps." If participants state they have a "flip phone" but this flip phone does not allow them to access the internet or download apps, this does not count as a smartphone and should be marked as "no" for not owning a smartphone.
- 11b. A desktop computer is a stationary computer that sits on a desk or table, while a laptop computer is a portable computer with a keyboard that you can use anywhere.
- 11c. A tablet is a portable computer, but unlike a laptop, it is typically flat, has a touchscreen, and does not have a keyboard.

For questions 12-12b, record whether participants have access to the internet at their house, apartment, or other place of living. If the response to question 12 is "No", go to question 13. Participants with internet access may have question 12a or question 12b marked as "yes" or both questions 12a and 12b marked as "yes."

12a. A cellular data plans allows you to access the internet from many places using a cell phone. Cellular data does not require having a router at home, instead, it connects to a nearby cell tower or satellite to provide internet access. Cellular data plans for your cell phone are offered by companies like Verizon, T-Mobile, Google Fi, or AT&T.

12b. Having access to the internet at home through an internet service provider can be obtained through broadband, satellite, or dial-up internet. Examples of broadband include cable, fiber optic, or DSL service. Comcast is a common cable broadband provider.

Whether the interviewer reads "also" in question 12b is dependent on the participant's response to question 12a. If the participant answers "yes" to question 12a (i.e., that they have internet access through a cellular data plan), then the interviewer should read "also" in question 12b. If the participant answers "no" to question 12a, then the interviewer should not read "also" in question 12b.

If the participant does not know the answer to any of questions 12-12b, assign a special missing value.

## **G.** Alcohol Consumption

<u>Script</u>: "Next, I am going to ask you about your consumption of wine, beer and drinks made with hard liquor."

13. Current alcohol consumption (yes/no). If the participant asks, or if the answer is not explicit, "presently" is defined as within the last 6 months.

# **H. Cognitive Complaints**

Script: "Now I have a question about your memory."

14. Please ask the question as written. The purpose of this question is to ascertain participants' self-reported memory function by asking participants about their own perception of their memory. If asked to clarify the question, indicate that we are asking about whether they have more difficulty remembering things (e.g. phone numbers, names of people they just met) than usual. Please code the responses as "Yes", "No", or "Do not know".

# I. Subjective Age

Script: "For the next question, please think about your overall life and health."

15. Read the question as written. Then read the three response options (i.e., Younger, Same, Older). If the participant states that they do not know how old they feel compared to their actual age, assign a special missing value. If needed, clarify that the participant should think about their overall life and health to answer the question.

# J. Unintentional Weight Loss

<u>Script</u>: "I would like to ask you a few questions about weight loss to track potential changes."

If there are concerns that some of these questions about weight loss have been asked previously, the interviewer can respond by saying, "You may have been asked some of these questions before, but it is important to make sure we have accurate information and to track potential changes that could have occurred since you were last asked these questions."

16a. Read the question as written. If the response to question 16a is "Yes", go to question 16b. If the response to question 16a is "No", go to question 17. If the participant does not know if more than 10 pounds have been lost during the last 12 months, enter 'Unknown' for question 16a and go to question 16c to determine if the participant was trying to lose weight. This will be informative when combined with objective measures of weight from the clinic exams.

16b. If more than 10 pounds were lost ("Yes" to question 16a), ask how much lower the weight is now than one year ago (question 16b) and go to question 16c. If more than 10 pounds were lost in the last 12 months ("Yes" to question 16a), but more than 10 pounds were regained during the same time period, code '0' in question 16b to indicate that the participant's current weight is not lower, but the same or higher than it was a year ago. If the participant reported losing more than 10 pounds in the last 12 months ("Yes" to question 16a) and gained back weight, but not as much as they lost, the net result of their loss/gain is recorded in question 16b. For example, if they lost 20 pounds in the last 12 months and regained 15 pounds during the same time period, '5' should be recorded in question 16b. The weight (loss) reported should be recorded in pounds as integers (and no decimal places) in question 16b. If the difference in weight is reported in fractions of a pound, please round down, without engaging the respondent for clarification; e.g., 0.5 pounds should be recorded as 0; 1.5 pounds should be recorded as 1.

If the participant does not know the answer to question 16b, assign a special missing value for this question.

16c. Read the question, recording whether the participant was trying to lose weight or not.

# K. Sleep

# Scripts: "Next, I will ask about your sleep."

The goal is to assess usual sleep habits. If the participant asks what time-frame is of interest, say that we want to learn about their usual sleep habits during the past month.

For times to be recorded in questions 17 and 18, if you enter time using 24-hour time format, for example, if you type in "16:00", CDART converts it to 4:00 PM. If you type in 4:00, then it defaults to AM, but you can change it to PM or type it in as "4:00 PM" exactly.

- 17. Ask the participant what time they usually get into bed and try to go to sleep? If they say that the time when they get into bed is different than the time they try to go to sleep (for example, if they watch TV or read in bed for several hours before trying to go to sleep), then ask them what time they usually try to go to sleep. Report the hours, minutes and time of day (AM/PM). If they say an hour without mention of minutes, then report "0 0" for the minutes.
- 18. Ask the participant what time they usually get out of bed to start the day? If they say that the time when they get out of bed is different than the time they woke up (for example, if they wake up and read the news in bed before getting out of bed), then ask them what time they usually wake up and start daily activities. Report the hours, minutes and time of day (AM/PM). If they say an hour without mention of minutes, then report "0 0" for the minutes.
- 19. In general, you are trying to assess the participant's perceived usual sleep quality with a single question. Read the question as listed: "How would you rate your sleep quality overall? Very good, fairly good, fairly bad, very bad." Feel free to repeat the response options, if that would be helpful to the participant.

## L. Physical Ability

<u>Script</u>: "These next few questions ask about how well you typically function on your own, which is without help from another person or special equipment such as a cane or walker. Do not include difficulties due to a temporary condition like a broken limb. For each activity I mention, please tell me whether you are able to perform this activity with no difficulty, with some difficulty, or you are not able to do."

Examples of special equipment include canes, walkers, lift chairs, and motorized beds. If the device is used to aid in physical mobility, e.g. walking, balance, transferring in and out of bed or chairs, it is considered special equipment. Because the participant does not have response cards, read the response options for each following activity (questions 2 – 13) until you are confident the participant recalls the response categories (no difficulty, some difficulty, unable to do it). If in the course of asking about the remaining physical activities the participant provides answers that deviate from the response categories requested, repeat the refrain (Would you say no difficulty, some difficulty, or you are unable to do it?"), or use another form of probing. The most helpful type of probing in this case would be channeling, such as "If you had to choose, which would you say: No difficulty, some difficulty, or you are unable to do it?" If a neutral form of channeling does not work it may be necessary to bracket the perceived level of difficulty reflected in the participant's response, such as, "does that mean a little difficulty or much

difficulty ..."? As for any interviewing technique, do not suggest an answer or paraphrase the respondent's words. If participants have difficulty understanding or hearing "much", the interviewer may use the wording "a lot" instead.

Participants who use assistance or special equipment should be queried about the degree of difficulty if/when they do NOT have assistance from another person or special equipment. The assumption in these situations is that the first response (e.g. no difficulty, some difficulty, unable, don't know/do not do) would be "some" or "unable", else they would not require assistance. Some respondents may say they use equipment intermittently but do not need it because of difficulty, or "I just keep a cane, but I don't need it". The interviewer should repeat the possible responses, "Would you say that you have *some difficulty* without the cane/equipment or are you *unable to do it* without the cane/equipment?"

If participant responds that "I don't do that", the interviewer should probe to determine if this is due to a health or physical problem. For example, for managing bills or cooking, if the participant responds "My wife does that", ask "Is that because you are not able to (prepare meals or manage the bills/bill paying)?" If the answer is "No, I just don't do it & have never done it," choose "Unknown or do not do". However, if s/he says, "I can't keep up with that anymore," or "my arthritis is so bad my daughter started doing it", choose "Unable to do".

#### M. Administrative Information

- 32. sAFU general interview questions completion status. Enter the code that describes whether or not the sAFU general interview questions were completed.
  - A. <u>Complete</u>: Direct contact was made within the given time frame. The contact provided all the questionnaire information they could offer. The contact is not required to answer every questionnaire item to have completed the interview.
  - B. Partially complete, contact again within window (interruptions): Direct contact was made, but the questionnaire could not be fully administered due to an interruption not because of a refusal. This status is not a final status, as the interviewer will be attempting another contact to continue the interview. The final sAFU General Interview Questions Completion Status for the given time frame must be a. Complete, or c. Partially complete; unable to complete within window (done).
  - C. Partially complete, unable to complete within window (done): Direct contact was made, but the questionnaire could not be fully administered in the given time frame.